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A Qualitative Inquiry of Social and Emotional Support for Students with Persistent Concussion Symptoms

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Abstract

Students who sustain concussions often struggle with social and emotional symptoms. Such symptoms can interfere with students' academic performance, relationships, and overall sense of well-being. This qualitative study involved interviews with eight adolescents and young adults who sustained concussions as youths and experienced significant social and emotional symptoms; six of the participants' parents were also interviewed. Grounded theory methodology was used to code the data, construct categories and identify themes, and develop a theoretical model of students' post-concussion social and emotional issues and potential sources of support. Categories of issues emerging from the interviews included anxiety/stress, depression/sadness, interpersonal difficulties/isolation, and irritability/moodiness. An exploration of barriers and facilitators of recovery revealed themes related to: factors at school, factors at home, medical care, and level of involvement with sports and athletic personnel. The theoretical model highlights important areas for development in school-based consultation to ameliorate students' post-concussion social and emotional symptoms.

Keywords: concussion, traumatic brain injury, anxiety, depression, grounded theory, consultation

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A concussion is a type of mild traumatic brain injury (mTBI) that can result in a constellation of cognitive, physical, emotional, social, and sleep-related symptoms, all of which may affect students' well-being and performance in school (Centers for Disease Control and Prevention [CDC], 2017). While most concussion symptoms dissipate in one to two weeks, 15-30% of children who sustain concussions experience symptoms lasting at least three months (Babcock et al., 2013). Often, these persisting issues are social and emotional symptoms, which may go unrecognized and untreated (Moser, 2007). This relatively unexplored symptom cluster is the focus of the present study.

Children with delayed symptom resolution report higher scores on anxiety and somatization scales, compared to children with early symptom resolution (Grubenhoff et al., 2016). In one study of over 400 pediatric participants, emotional symptom scores were higher than either neurocognitive or somatic symptoms when evaluated more than two weeks after a concussive injury (Joyce, Labella, Carl, Lai, & Zelko, 2015), suggesting that prolonged concussion symptoms may adversely affect students' emotional health. Adverse academic effects following a concussion, such as failure to complete schoolwork, difficulty keeping up with workload, and other cognitive symptoms may be linked to the onset of anxiety and depression (Sady, Vaughan, & Gioia, 2014). Such effects can be persistent. For example, in a sample of children and adolescents who sustained mTBIs, 11% developed a diagnosable anxiety disorder and 20% developed subclinical symptoms of an anxiety disorder in the six months after injury (Max et al., 2011). Student athletes reported increased depression scores up to 14 days after concussion; these symptoms coincided with neurocognitive difficulties, including impaired

reaction time and visual memory (Kontos, Covassin, Elbin, & Parker, 2012). A summary of 12 studies demonstrates a prevalence rate for depression after concussion of at least 35% (Busch & Albern, 1998). In addition to anxiety and depression, many students who sustain concussions experience social withdrawal and loneliness. A survey of adolescents on the impact of loneliness on perceptions of quality of life post-TBI found significant correlations between self-reported depression and perceived quality of life, and between loneliness and anxiety (Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2014). However, the links between these issues and factors that help and hinder their resolution are unclear.

A common recommendation made by physicians when exiting children from the emergency department is for both physical and cognitive rest. However, complete and prolonged rest may also prolong recovery, particularly for social and emotional symptoms. Silverberg and Iverson's (2013) extensive review of the literature suggested that lengthy periods of inactivity (particularly complete rest—staying in bed and avoiding any cognitive stimulation) following concussion may do more harm than good. While vigorous exercise can exacerbate symptoms and increase risk for an additional concussion, the negative consequences of complete inactivity can occur after three days. A better understanding of how students cope with the rest and recovery protocol might help inform school-based consultation strategies.

Most studies that have explored the experiences of individuals who have sustained brain injuries have focused on adults and/or individuals with more severe brain injuries (e.g., Gould et al., 2019; Karlovits & McColl, 1999; Paterson & Stewart, 2002; Salas, Casassus, Rowlands, Pimm, & Flanagan, 2018) or college athletes (e.g., Cover, Roiger, & Zwart, 2018). Participants in those studies described the way their social lives and overall quality of life were affected by their brain injuries. One of the few studies to examine the lived experience of children with TBIs

was recently published by Minney, Roberts, Mathias, Raftos, and Kochar (2019), who conducted a qualitative study on the service and support needs of children who sustained a mTBI. They interviewed elementary-aged children (ages 8-12) and their parents and found post-injury needs related to communication, family burden, continuity of care, and social and community support. The themes revealed in their interviews reflected both the children's and parents' need for information, emotional/social/community support, and follow-up care. Minney et al. concluded that dedicated and individualized mTBI follow-up services that build on family resources and their needs for information, emotional support, and referral may help improve post-injury outcomes. However, a deep understanding of the nature of social and emotional difficulties faced by students who have sustained concussions and factors that exacerbate or improve such symptoms—particularly in educational settings—remains unclear.

Given that when compared to adults, youth ages 5 to 18 are at increased risk for experiencing TBIs and prolonged recovery (CDC, 2017) and that each year approximately 250,000 children are treated in US emergency departments for sport and recreation-related injuries that included a diagnoses of a concussion (Gilchrist et al., 2011), it is clear that concussions affect significant numbers of students. The post-injury influence of social and emotional problems following concussion has both developmental and academic implications, thus warranting further research to help school personnel better understand how to assist students with social and emotional symptoms. While teachers report fair levels of knowledge about most concussion symptoms, they are less confident in their ability to recognize emotional symptoms and behavior changes related to concussion (Dreer et al., 2017; Graff & Caperell, 2016). This points to an important opportunity for school-based consultants to provide support.

The purpose of this project was to explore the following research questions: 1) What social and emotional symptoms and subsequent problems can arise after a student has sustained a concussion, and 2) What factors might ameliorate or exacerbate social and emotional symptoms? The aim of this project was to develop a model of understanding these issues and help identify potential sources of support. This information can help school-based mental health professionals consult more effectively with students, parents, educators, and health care providers when addressing social and emotional difficulties following concussion.

Method

Design

A grounded theory qualitative design was chosen for this study (Charmaz, 2006; Corbin & Strauss, 2014) to clarify participants' experiences with concussion, with an emphasis on social and emotional symptoms and what helped or hindered symptom resolution. This involved utilizing a constant comparative method to develop conceptual categories and an explanatory theory. Although some research has been conducted on social and emotional concussion symptoms, our understanding of how these affect students is in a formative stage. The complex and varying nature of challenges experienced by students who sustained concussions necessitated individual consideration of each student's path to recovery. Grounded theory is an effective method for developing a theory from the bottom up; it allows the theory to emerge from the data. Thus, analysis of interviews allowed for in-depth exploration of the social and emotional challenges experienced by students who sustained concussions, as well as an exploration of potential frameworks of support.

Participants

The researchers used snowball sampling by identifying cases of interest from "people who know people who know what cases are information-rich" (Marshall & Rossman, 2016, p. 115). To find such cases, a flyer was distributed to local educators and physicians who were asked to share information about the study with potential participants. Interested participants were asked to contact the primary investigator. We then proceeded to criterion sampling, including all interested participants who met the following criteria: they sustained at least one concussion and subsequently experienced significant social and/or emotional symptoms. Participants were interviewed until the researchers noticed theoretical sufficiency of data, hearing the same patterns repeated and sensing that little more would be gained through further data collection (Dey, 1999). At that point no further participants were recruited.

Eight students with self-reported and parent-verified histories of concussion participated in the study; six of their parents also participated in interviews. Student participants included three males and five females; all were from one Midwestern state. At the time of their interviews, student participants ranged in age from 13-20, having sustained their injuries between ages 11 and 19. All reported experiencing post-concussion symptoms, but were no longer acutely symptomatic. A requirement for participation was self-report of post-concussion social and/or emotional symptoms. Each participant was given a pseudonym for confidentiality.

Frances. Frances was a 16-year-old Caucasian female who sustained a concussion while playing goalie for her high school lacrosse team at age 14. Frances experienced headaches, memory loss, difficulty concentrating, dizziness, and sensitivity to light and noise. She experienced increased stress regarding school, but reported that injury did not significantly affect her long-term social-emotional health.

Joe. Joe was a 17-year-old African American male who sustained two concussions. He reported sustaining his first concussion at the age of 13, after an altercation with an older football player; however, he did not see a physician for a diagnosis. Joe reported sustaining a second concussion at age 14. The injury occurred during a statewide wrestling match, after an opponent threw him to the ground. Immediately following his concussions, Joe experienced headaches, memory loss, fatigue, disorientation, and sensitivity to light and noise. He continues to struggle with memory and focus. Joe also experienced an increase in irritability, mood swings, and feelings of isolation and depression; he continues to struggle with these social-emotional issues. Joe was diagnosed with a specific learning disability for reading prior to his concussions and had an Individualized Education Program (IEP) in place.

Stephen. Stephen was a 13-year-old Caucasian male who sustained two concussions over the past two years while biking. Stephen was previously diagnosed with Psychogenic Nonepileptic Seizures (PNES), as well as generalized anxiety. After his concussion, Stephen suffered from memory loss, difficulty concentrating, slower movements/cognition, nausea, and sensitivity to noise. Stephen struggled with an increase of anxiety and irritability, and continues to struggle with these social-emotional issues.

Elizabeth. Elizabeth was a 17-year-old Caucasian female who sustained multiple concussions (two diagnosed), most while playing on her high school lacrosse team. Elizabeth suffered from moderate headaches, nausea, dizziness, fatigue, slowed movement/cognition and difficulty concentrating and recalling information. Elizabeth experienced an increase in feelings of anxiety, frustration, and feelings of inadequacy.

Ashley. Ashley was a 16-year-old Caucasian female who sustained two concussions over the last year while playing for her high school basketball team. Ashley suffered from severe

headaches, nausea, dizziness, fatigue, memory loss, and difficulty concentrating. Ashley experienced irritability, mood swings, and feelings of isolation, depression, and anxiety.

Courtney. Courtney was an 18-year old Caucasian female who sustained a concussion while playing softball when she was 15. Courtney suffered from severe headaches, nausea, extreme sensitivity to sound and light, fatigue, and difficulty concentrating. She experienced irritability, feelings of isolation, depression, and anxiety. Courtney still struggles with her memory and concentration as a result of her injuries.

Kara. Kara was a 19-year-old Caucasian female who sustained a concussion while playing for her high school soccer team. Kara experienced severe headaches, vertigo, fatigue, memory loss, difficulty concentrating, and sensitivity to light and noise. Kara also struggled with anxiety, feelings of inadequacy, isolation, and depression.

Matthew. Matthew was a 20-year-old Caucasian male who sustained multiple concussions while playing football over the last four years (seven diagnosed; 12-18 in total by his own estimates). Matthew experienced severe headaches, fatigue, sensitivity to light and noise, slowed movements/cognition, and difficulty concentrating and recalling information. Matthew struggled with feelings of inadequacy, isolation, and depression, as well as a heightened emotional sensitivity. Matthew continues to struggle with the social-emotional issues aggravated by his injuries.

Parents. Additional research participants included parents of six interviewees. Family member participants included Frances's mother, Joe's mother, Stephen's mother, Elizabeth's mother, Ashley's stepmother, and Courtney's mother. Kara and Matthew were in college at the time of their interviews and their parents did not participate.

Instruments

The interview protocols were designed by researchers based on questions raised through the literature review, which indicated social and emotional symptoms can be problematic and that there are opportunities to ameliorate such symptoms. Participants were asked questions that were designed to elicit responses about their overall concussion experience, including: *Tell me about your concussion*; *Tell me about your symptoms right after the concussion;* and *Tell me about symptoms that lasted for more than a few weeks after your concussion.* Participants were then asked more focused questions related to social, emotional, and behavioral symptoms of concussion, *Tell me about any negative feelings you experienced after your concussion,* as well as things that hindered and helped their recovery process: *What made your symptoms worse? What was most helpful following your concussion?* Participants were encouraged to tell their stories and to provide specific examples of how symptoms interfered with daily functioning, and to describe what was most helpful in improving symptoms. The interviews all concluded with "*Is there anything else you want to tell me about your concussion(s) that you think will help me better understand how to help other students?*" This gave participants the opportunity to share any additional information related to their experience with concussion that they wanted to share, which they may not have felt was adequately conveyed during the interview.

The parent interviews provided a means of triangulation of the student interview data was conducted. Triangulation is the act of bringing more than one source of data to bear on a single point (Marshall & Rossman, 2016); thus, the parent interviews served as a means of confirming the students' accounts of their injuries and subsequent symptoms. Parents were asked similar questions to those in the child interview, with slight variation in wording (e.g., "*Tell me about your child's concussion*.").

Research Team

In accordance with the principles of grounded theory, researchers actively shape the research process and interact with the data (Charmaz, 2006). Therefore, reflexivity—wherein the researchers' perspectives, experiences, and values are examined—is essential. The authors themselves have no personal experiences with significant post-concussion social-emotional symptoms; however, each investigator brought a unique perspective to the study. The primary investigator has worked in a school setting with students who sustained brain injuries and she has conducted numerous studies on concussions in school-age children; the second author's research focuses on anxiety and she teaches consultation to school psychology graduate students; the third author conducts work and research in health and sports science, including sport-related concussions. Our research team also included two trained graduate assistants who conducted the interviews and two trained undergraduate assistants who transcribed the interviews.

Procedure

The primary investigator (PI) trained the research assistants by reviewing and discussing interview techniques and having them practice interviews on one another. Research assistants then audio recorded practice interviews with individuals who were not participants in the study. The PI provided corrective feedback based on the recordings to assistants prior to data collection. The PI also instructed the research assistants to not refer to information learned from the parent when interviewing their child and vice-versa.

After gaining approval from the Institutional Review Board, participants were recruited for the study. After securing informed consent, interviews were conducted in a quiet location of the participants' choice, most often his or her home (with parents home but not in the interview room). In some cases, students were interviewed concurrently with their parent(s) in separate

rooms, using different research assistants. In other cases, the parent interview occurred immediately before or after the student interview, using the same research assistant, without the child present. The interviews lasted approximately 30 minutes (ranging from 22 to 53 minutes). The semi-structured interview format and strong training of research assistants helped ensure that the research assistants did not alter their interviews with parents based on interviews with the children and vice-versa. Artifacts included the interview questions and field notes taken by interviewers.

During the interviews, participants described their experiences with concussions and persistent symptoms, particularly social and emotional difficulties. They also discussed factors that helped or hindered recovery. Follow-up questions prompted for specific examples of how symptoms interfered with daily functioning and what was most helpful in improving symptoms, particularly at school. At the end of each interview, the interviewer summarized key points and allowed participants to clarify or add any information. To enhance trustworthiness of data collection, this study utilized member checking as a way of asking participants if we "got it right" (Marshall & Rossman, 2016, p. 230). Each interview concluded with the interviewer summarizing the main points of the interview and asking participants if the summary was accurate.

Interviews were digitally recorded and later transcribed for analysis. Transcriptions were word-for-word. Extracted fragments were later edited to remove unnecessary fillers (*like, you know, um, just, I mean*) in order to improve readability.

Data Analysis

Data were analyzed according to principles of grounded theory (Corbin & Strauss, 2014; Glaser & Strauss, 1967). Two of the researchers did open coding by consensus to find patterns

and key concepts in the data. In this iterative process, we independently reviewed the transcripts to make sense of the data and communicated with each other in order to identify and come to consensus on the conceptualization of initial codes. Throughout initial coding, we wrote memos to raise questions about the data and record initial ideas for potential emergent categories and themes.

To enhance methodological rigor, credibility checks were undertaken, which included an independent researcher applying the definitions for each code to the data to check for consistency in meanings and application. This was calculated as a percentage of agreement between coders (number of agreements divided by the number of agreements + disagreements). Miles and Huberman (1994) suggest intercoder agreement of 80% is adequate. Our overall level of intercoder agreement for the student interviews was 91%; our intercoder agreement for the parent interviews was 86%. Differences were examined and the raters came to a consensus on codes for which there were discrepancies.

Once the research team was satisfied with the clarity of codes, they were grouped into conceptual categories and themes that reflected commonalities among the codes using axial coding (Corbin & Strauss, 2014). In this process, we related codes to each other through a combination of induction and deduction, working back and forth from the emerging grounded theory to specific clusters of data, back to the emerging theory with modifications, and so on (Marshall & Rossman, 2016). The result was a summary of descriptors which reflected the participants' social/emotional symptoms as well as conceptualizations of factors that they felt exacerbated and/or alleviated social and emotional symptoms. As we saw and heard the same patterns repetitively and observed alignment of our participants' social and emotional symptoms with those discussed in previous literature, we discussed whether more could be gained from

further data collection. While additional interviews may have yielded interesting anecdotes or new information, our analysis yielded categories fitting with both our data and previous studies.

Coding and analysis of the transcripts by multiple evaluators enhanced trustworthiness of data analysis by providing intercoder reliability. As a final step toward improving the trustworthiness of data analysis, we employed peer debriefing. This involved the primary investigator meeting with the research team to get reactions to case summaries, data analysis, and report drafts. The team collaboratively fine-tuned the clarity and logic of interpretations.

Results

In exploring the social and emotional issues related to concussion, analysis of interview transcripts revealed four broad categories: anxiety/stress, depression/sadness, interpersonal difficulties/isolation, and irritability/moodiness. An exploration of variables affecting symptoms (barriers and facilitators of recovery) revealed themes related to: factors at school, factors at home, medical care, and involvement with sports and athletic personnel. Grounded theory methodology was followed to generate a theoretical model based on the data (Glaser & Strauss, 1967; Figure 1). This model illustrates the relationship between social-emotional symptoms and ecological systems that serve as potential barriers and facilitators of recovery, with school-based consultants providing the supporting framework.

Results are presented across cases. This cross-case analysis highlights commonalities and discrepancies among participants, as well as between student and parent accounts. While some qualitative studies present a separate subsection of contrary findings, we chose to thread these throughout each subsection. For example, when presenting factors at home that students perceived as affecting their recovery, we discuss both home-based barriers and home-based facilitators. When reading these accounts, it is important to keep in mind that participants varied

in age, number of concussions, pre-existing conditions, and lapse of time between injury and study participation. Such variables can affect their experiences and recollections.

Social and Emotional Issues

Anxiety/Stress. Much of the students' anxiety and stress related to academic and social situations. For example, Frances stated, "My grades started to drop. So I just kind of got stressed out about that." Her mother relayed that the neuropsychologist said, "I don't think Frances has anxiety that's causing memory issues. I think she has memory issues, and that's causing anxiety."

Stephen shared his experience with post-injury anxiety, stating:

> I've always been, in school, the teacher's pet or something, the 'good kid,' never gets in trouble. And I never forgot a homework assignment or turned one in late and so that was kind of an important thing to me. And this year [after the concussion] . . . everything was different . . . I had very much anxiety for forgetting homework.

Absences related to the concussion were also an issue for Elizabeth, who said, "I don't know if it was just the situation or had to do with the concussion, but missing out on school really stressed me out because I haven't missed a day of school all three years."

Matthew, a current college student reflecting on his high school concussions, shared academic stressors; he also described anxiety related to social situations, elaborating:

> Afterwards I was very, very nervous . . . I never was one to think about the words that I said when I texted or I wasn't like a big texter, but then I can remember just freaking about letters and if a word sounded good or stuff, just dumb stuff like that.

Courtney described stress related to sensory overload: “I would get overwhelmed really easily . . . I would walk into school and just start crying ‘cause there would be so many people talking in the hallway.”

Depression/Sadness. Ashley compared her pre-injury to post-injury emotions: “Before then, I was a little sad from time to time . . . But it was never as bad as [after] I got hit.” She elaborated that “everything was different. Even though I had been sad in the past or lonely, it worsened. And my parents recognized [it] especially.” Her stepmother shared, “[Ashley] would cry at night, hysterically. And sometimes at 1:00 in the morning, we would wake up. . .she had just insane, insane emotional outbursts that were very not typical.”

Kara’s despondency centered on her slow recovery. She stated,

> I went [to a functional neurologist] every single day for many months and that was when I felt super frustrated. I was seeing no improvement and just [felt] like, “What’s wrong with me? Why can't I get better?

Because Kara’s parents saw a significant difference in her personality, Kara reported that they had her go to therapy from late high school until she started college.

Elizabeth felt she was letting herself and others down: “I felt like I was letting [my coach] down and letting my team down by not being there. And even my teachers, I was disappointed in myself because I was like, I can’t even do these simple math problems.” Her mother shared, “[Elizabeth] was pretty sad. . . . . When she didn’t bounce back quickly, I think she got a little depressed and sad and all those things. I think it just kept compounding day after day after day.”

When discussing his own issues with sadness post-concussion, Matthew described the difference from pre-injury to post-injury, as well as family variables:

> I was already a pretty emotional kid before I got that first one. But everything just made me sad. I didn't understand why but no matter what it was, it was kind of, there was always a negative side to it. That negative side just took over. . . It really sucked because it's not an injury that people can like visibly see.

Interpersonal Difficulties/Isolation. Joe's mother linked his sadness to his social isolation, stating: "He went through a chain where he was just sad and depressed and would be a hermit. We used to have every weekend 7 to 10 guys at our house and they used to have fires and everything." Joe described his perceptions of these changes: "I used to like being at parties and now I don't like being around big crowds because I feel like somebody is out to get me, I just don't like being around people but I don't know why."

Kara also did not want to go out with friends as much, and as a result experienced changes in her relationships:

> I definitely began to lose friendships and lose touch with my family because I was just like, 'I can't.' Every single day I would wake up . . . with somebody pushing their fist against my brain. . . So I kind of just stopped going out with my friends and I was super irritable with my family because they didn't really get it.

For Courtney, this led to long-lasting changes in friendships:

> I think being stuck in a room for that long, I learned a lot of who were my actual friends . . . which was really hard 'cause it ended up being a lot fewer. I would have a couple of friends who would come over. My birthday was 20 days after that or something so my friend came and had a picnic in my living room with me. So I definitely felt a lot more isolated and a lot of my friends had kind of just forgotten about me.

Courtney's mother shared her perception of Courtney's interpersonal difficulties:

> [Courtney] worried about her school. She worried about missing homecoming. She was very, very social before the concussion, had a lot of friends. So she started stressing about a lot of things because she couldn't do stuff. Even if she tried to do social activities with her friends, it hurt her head and she'd have to leave. She got one of her teachers angry at her because she wasn't coming to school, but he saw her in town one day. So I had to educate the school on the importance of her still having social life.

Irritability/Moodiness. Several participants disclosed that they became more irritable after their concussion. Elizabeth linked this emotion to the previously discussed interpersonal changes, saying: "I think I was just more irritable in general. Sometimes I wouldn't want to go out with them because I didn't feel like doing anything."

Her mother concurred: "I would say that was probably a good eight to ten days . . . that she was very irritable. [Elizabeth] was very frustrated that she was injured and that it wasn't getting better quickly."

Joe described a lack of self-awareness of his irritability initially, noting a peer would "say mean stuff to me, and I feel like I am more self-conscious about myself, so I get upset when they talk about me, so I say something back worse to them." He elaborated, "I didn't notice it, but a lot of people were telling me that I was getting more mean and that I didn't care what I said, like I didn't watch what I said and stuff. And I didn't notice that I was losing a lot of friends because of that." When interviewed, his mother added, "Once school started coming around, obviously he had to get up, he would get irritated very easily, he would be mean at times and then times he'd break down and cry."

The concussion affected Stephen's mood at home with his sibling: "I was more irritable with my brother . . . I'd get mad worse,. . . I'd yell more. I'd yell louder." His mother's interview validated this: "He'd get so angry or he'd get paranoid like 'Don't touch me! Don't touch me!'"

Perceived Factors Affecting Symptoms

Participants discussed a number of factors that they felt exacerbated and/or alleviated social and emotional symptoms, including factors at school, factors at home, medical care, and level of involvement with sports and athletic personnel:

Factors at school. Coordinated academic adjustments helped alleviate symptoms. Frances stated, "I got a doctor's note for tests and stuff. . .So I could have more time," and "Our counselor would . . . talk to my teachers about the accommodations that my doctors gave me."

Joe, who had an IEP for reading prior to his concussion, also described helpful academic accommodations, such as audio books and taking test in a separate location. His mom said: "[Joe] had an awesome intervention specialist . . . She was amazing. She helped him out tremendously." However, while the intervention specialist was helpful, "The communication throughout the school has not been there. I went in, I talked to the principal, I talked to their teachers. We've had some issues."

Elizabeth described a specific teacher's assistance: "[My English teacher] was super understanding and I think that made me feel less stressed. At least with her class because she just she understood." She also described support from an administrator, as well as the lack of the counselor's involvement:

> It was right before AP testing that [my concussion] happened. So I had to talk to [the vice-principal] about it. When I returned to school I went to his office and I would talk to him and say, 'Hey I like can't take this test.' And so he was helpful and he understood.

> But our counselors aren't really much of counselors. They just kind of schedule for us, they don't, they're not there for emotional support as much.

Courtney's teacher was particularly accommodating:

> My teacher would set up a yoga mat on the ground in there for me because she thought the floors were gross, so getting to take naps in there if I needed a break from school or things like that made it so I could last at school for more than a period or so. So that was definitely helpful and then also my teachers weren't allowed to give me busy work . . . so the fact that my work got put down to a minimum was really helpful.

Kara's experience was that garnering support from school took time. She said school staff members were:

> Definitely overall very nice but it took a while. It took letters. It took convincing. It took them having to have meetings . . . I went to my school counselor and was like 'I don't know, I'm in this math class . . . I'm looking at the board and they're not registering in my brain. I can't do the homework, I'm failing the tests.' And she was very like, 'Well, just go ask for extra help.

Factors at home. Several participants described support at home as an ameliorating factor. For example, Ashley said, "Mostly parents pushed me through it. I mean they're definitely my number one motivators and if there are obstacles in the way they are always like pushing me. They kinda always just gave me a drive."

Elizabeth spoke positively of her parents, but also expressed frustration at how they kept her isolated during recovery, "My mom was already saying 'Don't go do things with your friends, you need to focus on you.' Which was right but at the same time . . . it was starting to wear on me to be secluded off." She elaborated,

> I would try to reach out to them when I could, like when I would have fifteen minutes on my phone but fifteen minutes isn't long enough to talk. . . My mom would just say 'Don't use your phone' and she was home the first day so she took my phone. She gave me fifteen minutes to answer seventy text messages. 'Cause people thought I broke my nose at first. So I had to tell everyone 'Nope, just a concussion. I'm fine.'

Matthew also described how stressors at home were a factor in his recovery:

> At home I would forget if my parents asked me to do something I would forget about certain small stuff but then that would turn into my parents thinking I was irresponsible or was purposely not listening to them or stuff like that, so it was tough in that regard because your people are getting mad at you for stuff that you feel like you can't control.

Other variables at home, including tensions between her parents, were a factor in Ashley's social and emotional symptoms: "The situation that I was going through at that time probably worsened it. My parents were going to court and I was really . . .They argued all the time and I was caught in the middle at time."

Ashley's stepmom also brought up this issue in her separate interview, stating, "She bears a lot of trying to keep both sides happy."

Medical care. Kara stated one helpful factor was communication between her neurologist and school: "I had to drop out of my math class and I had to change my schedule so that I could go in the nurse's office after every class. All of those school accommodations [the neurologist] helped me get."

Matthew concurred:

> I also went to [a local Children's Hospital] and did the neuropsych exam and it was helpful knowing that there is something . . . wrong [which] kind of helped dealing with it

> because before that it was only me that thought there was something wrong and you think you're crazy.

Outside counseling was also helpful for Matthew: "Just understanding your feelings and being able to talk about your feelings; that really helped that too." He also described self-medicating: "I did self-medicate with marijuana, which at the time it helped both with stress wise and symptom wise like headaches and functioning. Not to say that I was walking around stoned all the time, but just at the end of the day doing that, it helped me sleep a lot, it helped it just helped make me feel a lot better the next day."

Kara did not see her prescribed medication as helpful: "I went to my doctor and she put me on medicine. . . but it was awful and it made me feel like a zombie, just everyday waking up. It did not help in any way."

Courtney had mixed feelings about her medical care:

> I tried a bunch of things at once so it was really hard to tell exactly what did something. I think that a lot of the meds I took [specific medication name redacted] which I took for headaches and still take now, was really helpful . . . The chiropractor or the balance therapy, they didn't really do much.

Her mom talked at length about how Courtney struggled with her medical care providers: "Whenever we would go to the doctor she would cry. They kept telling us that it was all in her head. That she needed therapy. And that it wasn't the concussion causing any of her behaviors, causing her headaches."

Level of involvement with sports and athletic personnel. Elizabeth struggled initially with physical restrictions post-concussion: "When I couldn't exercise, I didn't have an outlet so I

would just sit in my room and think. And I think something, thinking is my worst enemy." Her athletic trainer was a key factor to her recovery:

> I think my trainer [name redacted] actually was really really helpful . . . I would go into her office and she would take my symptom score and I took the IMPACT test . . . she would just talk to me and ask how I was doing. . . she's a really caring person.

Elizabeth's mom had a similar perception of the athletic trainer as a key facilitating factor: "I think probably the most helpful was the trainer because she was extremely knowledgeable. She wasn't really concerned about getting [my daughter] back into play more than she wanted her to be healthy."

Ashley had a similar experience with the athletic trainer being involved and monitoring Ashley's recovery. Ashley acknowledged the benefit of a break in physical activity. She later elaborated that the athletic trainer was another key helper:

> [He] explained to me what was happening with the post-concussion syndrome and concussions in general and he helped me a lot like saying things like I should sit out and kinda comforting me, cause I still wanted to go out and play and I still wanted to do certain things. But he kinda held me back and explained what was best and helped me a lot to slow down and look at the big picture.

Joe's mom described the significant shift in identity that Joe dealt with after his concussion. She described a phone call from her son in which he "was crying. . . he was like, 'you have nothing to be proud of me about. Like you can't talk to people and tell them I'm a state placer or I'm a football this or that.'" Yet Joe described some positive changes that occurred when he changed his level of involvement with sports and discovered other interests.

"I've been hanging out with other people lately since I stopped wrestling, I have got into the hobby of fish and fish tanks."

Discussion

The findings of this study reflect in-depth analysis of eight students' experiences with persistent social and/or emotional symptoms following a concussion, with the aim of developing a model of understanding these issues and potential sources of support. Commonalities and differences among participants emerged from the data. This highlights the importance of viewing each student case of concussion separately—not over-generalizing students' experiences—and the importance of collaborating with parents to help them understand their child's unique symptoms and needs. Common challenges included feelings of stress, sadness, isolation, and moodiness. The students could tell they felt and functioned differently than they did before their injuries.

Among the most noteworthy findings were that many of the strategies commonly used to help students recover also seemed to exacerbate their social and emotional symptoms. For example, cognitive and physical rest protocols can help decrease physical symptoms, such as headaches, but they also cause students to miss school and be isolated from their peers. This illustrated Silverberg and Iverson's (2013) finding that rest protocols can have unintended consequences. Further, participants reported that changes in functioning related to their concussions exacerbated emotional problems. Memory problems and slower-than-expected recovery triggered persistent social-emotional symptoms, particularly anxiety.

Most participants described difficult social situations, including restrictions on activities and friendship changes. Feelings of anxiety, depression, and isolation may be due to a combination of new cognitive difficulties, academic stressors, and/or functional impairments that

limit interaction with others. Participants who maintained positive social connections with old and new friends described fewer persistent social and emotional issues. Social and emotional issues may be exacerbated by well-intentioned but overly restrictive post-concussion rest protocols. While some restrictions are necessary post-concussion to facilitate recovery and protect against re-injury, students often feel frustrated by restrictions on freedoms they previously enjoyed (e.g., driving, going to movies) and isolated from peers due to restrictions on recreational, sports, and social activities.

Another issue that emerged from the data was that people in participants' lives who did not understand the student's experience tended to make things worse, while supportive and informed parents, friends, school personnel, and athletic personnel made things better. This supports Minney et al.'s (2019) finding that both children and their parents need to receive information, emotional, social, and community support, and coordinated follow-up care. Our participants reported that athletic trainers were particularly helpful. Not surprisingly, athletic trainers generally know more about concussion symptoms and recovery than other school personnel (Wallace, Covassin, Nogle, Gould, & Kovan, 2017). The fact that the students' injuries were "invisible" often contributed to a lack of understanding from others. Interestingly, a few participants mentioned school counselors, but did not describe them as key providers of help and support. No participants mentioned school psychologists. Thus, these two groups of professionals may be under-trained or under-utilized in supporting students' concussion recovery.

Coordination of care among professionals, parents, and the recovering student was identified as a supportive factor. Participants described doctors sharing recommended school-based adjustments that, when followed, alleviated symptoms. Students appreciated such

strategies, along with deliberate plans to minimize stressors at home and school, during recovery. A collaborative care approach to supporting youth with persistent post-concussive symptoms that effectively integrates medical and behavioral health care is a promising model for symptom reduction (McCarty, Zatzick, Stein, Wang, Hilt, & Rivara, 2016). Focusing primarily on collaboration and coordination, school-based consultants can serve as the primary mediator across the ecological systems in which the student functions (i.e., home, school, medical; Truscott & Albritton, 2011). This may include assisting with disseminating important information about a student's injury and symptoms to teachers, administrators, and coaches. School-based consultants can also make recommendations for helpful classroom accommodations as well as a plan for gradually withdrawing them as symptoms subside. They can then report back to outside medical providers on the student's progress and symptom resolution or persistence.

The theoretical model that emerged from our data (see Figure 1) illustrates the student affected by social-emotional symptoms. These are inextricably linked with one another and they are nested within the ecological systems of home, school, the medical community, and the child's athletic community. The model represents a pool in which the weightier socioemotional symptoms can make the student feel overwhelmed ("drowning"). Supports, strategies, and people within the ecological systems can positively affect the symptoms and buoy up the student. The school-based consultant wraps around these systems, providing integration of care.

Implications for School-Based Consultation

Given our emergent findings, it is evident that improvements in care coordination are needed, particularly in supporting students with persistent post-concussive social-emotional symptoms. The experiences reported by the participants in our study demonstrate uneven

communication and a lack of clarity in developing and implementing a post-concussive care plan. This is not surprising given the poor knowledge of concussions demonstrated among school staff (Glang, McCart, Moore, & Davies, 2018) and the lack of communication across various systems of care that is commonly observed (Power, Blum, Guevara, Jones, & Leslie, 2013). School-based consultants, such as school psychologists, regularly work with students with chronic health conditions, for which consultation with medical providers is necessary. Ongoing collaboration across systems is noted as essential to achieving positive psychosocial and health outcomes for students with medical needs (Power, Glaser, & Ouimet, 2011). As opposed to chronic health conditions, for which symptoms are often observable and long-term care plans are needed, concussions are often seen as 'invisible' injuries with symptoms that are time limited. Persistence in symptoms, specifically social-emotional difficulties, are not widely understood. Perhaps given the fairly transient nature of most concussions (i.e., symptom resolution typically occurs within a few weeks), the communication that occurred between medical providers, school staff and families described by participants, reflected this belief. Moreover, the persistent symptoms experienced by participants were not immediately connected back to the concussion, resulting in inconsistent communication and uneven care.

Several frameworks exist for establishing collaborative relationships between school and health care professionals (e.g., conjoint behavioral consultation, CBC; Sheridan et al., 2009; the Eco-Triadic Model, Shields & Heron, 1995), a review of which is beyond the scope of this article (see Shaw, Glaser, & Ouimet, 2011 for a review). In considering our findings alongside the relevant frameworks, there is no single approach that fits best. The Biopsychosocial Model described by Grier and Bradley-King (2011) is perhaps the best fitting framework. In this model, which emphasizes frequent and ongoing communication and collaborative problem solving,

school-based consultants serve as a liaison between ecological systems (Grier & Bradley-King, 2011), ensuring that necessary environmental adjustments and academic accommodations continue to change as recovery occurs.

School-based consultants are urged to initiate and facilitate a home-school partnership as soon as a case of this nature emerges. Opening lines of communication with both parents and medical providers will allow for better coordination across settings. This includes developing and communicating a plan for environmental and academic adjustments at school, which are important for proper symptom resolution and transitions that result in less stress for the student and parent. Depending on the severity of the child's post-concussive symptoms, this may include establishing a plan for returning to play and learning, identifying necessary accommodations within that gradual plan, and planning and implementing any intervention strategies to assist with persistent social-emotional symptoms. Finally, practitioners consulting on concussion cases should consider that each concussion in unique; progress monitoring is needed to evaluate the effectiveness of strategies employed.

Strategies for school-based consultants. While cognitive exertion and vigorous exercise can result in persistent symptoms (Wells, Goodkin, & Griesbach, 2016), complete inactivity can result in negative consequences (Silverberg & Iverson, 2013), many of which were shared by our participants. Thus, a gradual, monitored, supported return to academic, social, and athletic activity is recommended. Based on difficulties shared by our participants, following are several strategies school-based consultants can use to support students with concussions:

1) To prevent social isolation, help students with concussions find ways to occupy their time that do not include physical or mental strain. For example, a student might join the art

club for a creative outlet or become a team manager so they can stay connected to their sport while not actively practicing or playing in games.

2) Directly teach students evidence-based coping strategies for managing stress and anxiety that might arise during the recovery, such as progressive muscle relaxation, guided imagery, deep breathing, or mindfulness.
3) Provide a comfortable space where students can go to decompress or talk to a trusted adult, such as the school counselor, school psychologist, or school nurse.
4) Help students identify and eliminate stressors, such as unnecessary schoolwork, pressure from friends to go out, or pressure from teammates to "get back into the game." For example, a teacher might not realize how stressful a backlog of assignments is for a student. Excusing non-critical assignments and minimizing requirements for others can help alleviate students' post-concussion anxiety.
5) Create plans that allow students to participate in social and milestone events, such as birthday parties and prom, without excess exertion. Such plans might include abbreviated attendance at such events; for example, attending an hour of a party, but eliminating the sleepover. While limited screen time is often recommended during concussion recovery, consider allowing use of texting and/or social media where time can be monitored (e.g., require that the device stay in the kitchen, to be used for short periods of time).

Consultants leading the trained concussion team. A trained, collaborative team facilitates coordination of care across settings. In addition to the student and parents, such a team typically includes school personnel, such as teachers, administrators, school nurses, school psychologists, and school counselors; medical professionals, such as neuropsychologists, neurologists, and pediatricians; and athletic personnel, including coaches, athletic directors, and athletic trainers

(Davies, 2016). This team, equipped with the dual knowledge of concussions and associated difficulties as well as effective practices for delivering consultation services, can provide much needed services to an often-underserved population of students.

School-based consultants, such as school psychologists, are in a key position to help lead the team effort of implementing and monitoring strategies to mitigate the social and emotional issues that can arise after a brain injury. Thus, we must have a workforce of educational professionals who understand brain injuries, so they can facilitate a team-based concussion response. It is also important that students themselves—particularly student-athletes—are trained to recognize and respond to concussions. For example, Elizabeth's remark that people thought she broke her nose, so she had to tell them "Nope, just a concussion. I'm fine," is telling. It reflects a line of thinking whereby an injury to the brain is not as serious as a broken nose. Elizabeth minimized her injury as "just" a concussion and said she was "fine" when, in fact, she had numerous persistent symptoms.

Limitations and Future Research

Qualitative studies are intended to provide information about the quality of relationships or situations. The small sample of participants interviewed for this study precludes generalization to all students who sustained concussions. The primary interview participants were older adolescents. Significant insights could be gained by including younger students. Further, because we conducted face-to-face interviews, our study sample was limited to participants in one Midwestern state. Thus, our findings might not be representative of students in other regions.

The interviews relied largely on participants' recollection of symptoms and experiences. Some participants' memories may have been compromised by their injuries or the passage of time, or both. Therefore, readers should be mindful that the intent of this study was to provide an

understanding of social and emotional effects of concussions through the eyes of those who experienced them. This is particularly important for effective consultation, as it can help school-based consultants better understand the complex layers of concussion recovery and the unique issues faced by individual students and their families.

There were also factors that were not directly examined in the study which could influence the findings drawn from the interviews. For example, participants varied in the number of concussions experienced, the duration of their symptoms, the lapse of time since injury, and whether they reported having other conditions prior to the injury. Such variables could have contributed to their symptoms and rate of recovery. Future research might include in-depth examination of how these variables are related to social and emotional symptoms and recovery. Further, despite safeguards to enhance trustworthiness of the data, it is possible that participants withheld some of their experiences. Finally, interviews were conducted by multiple research assistants, which may have affected variability of the data. To safeguard against this unintended effect, their recorded interviews were reviewed by the primary researcher.

Conclusion

Students who sustain concussions may experience social and emotional symptoms that adversely affect their relationships, mental health, and academic performance. Such symptoms might be alleviated through a gradual return to activity, with evidence-based consultative support and collaborative coordination of care across parents, medical providers, school personnel, and athletic personnel. School-based consultants, such as school psychologists, can be key leaders in supporting recovering students and in equipping parents with effective strategies to manage their child's social and emotional challenges related to concussions.

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APPENDIX
Interview Questions—Students

Question type	Question
Introductory comments	"Thank you for your willingness to participate in this interview. My name is ___and I am helping with a research project about concussions. As you know from the form you signed, your participation today is voluntary and you can skip a question, ask to take a break, or stop the interview at any time. All I ask is that you provide honest answers. I'm looking forward to hearing about your experiences. Do you have any questions before we get started?"
Opening	"Tell me about your concussion." • Prompt for concussion history, age of injury, mechanisms of injury, and perceived severity • Tell me about your symptoms *right after* the concussion • Tell me about symptoms that lasted *for more than a few weeks* after your concussion
Transition	*If not addressed with last question…* "Tell me about any feelings of *anxiety* you experienced after your concussion" Repeat for *depression, irritability, social issues/isolation*. Tell me about your ___ (anxiety/depression/etc) before your concussion" *(prompt for whether this was an issue before the injury and, if so, to what degree*)
Key	• In thinking about your (*anxiety/depression/irritability/social issues*), what made those symptoms worse? • What was most helpful following your concussion? (*prompt for what helped at home and school, who were helpful people, and what specifically they did*). • *Encourage the participant to tell his or her story and to provide specific examples of how symptoms interfered with daily functioning and what was most helpful in improving symptoms.*
Conclusion	• In 2-3 minutes, briefly summarize the main points of the interview and ask if the summary is accurate. • When summary is completed, say, "Is there anything else you want to tell me about your concussion(s) that you think will help me better understand how to help other students?" • "Thank you for participating in this interview with me. I may be in touch at a later date to ensure that all the information recorded was an accurate representation of your experiences."

Interview Questions—Parents

Question type	Question
Introductory comments	"Thank you for your willingness to participate in this interview. My name is ___and I am helping with a research project about concussions. As you know from the form you signed, your participation today is voluntary and you can skip a question, ask to take a break, or stop the interview at any time. All I ask is that you provide honest answers. I'm looking forward to hearing about your experiences. Do you have any questions before we get started?"
Opening	"Tell me about your child's concussion." • Prompt for concussion history, age of injury, mechanisms of injury, and perceived severity • Tell me about his/her symptoms *right after* the concussion • Tell me about symptoms that lasted *for more than a few weeks* after your child's concussion
Transition	*If not addressed with last question…* "Tell me about any feelings of *anxiety* your child experienced after his/her concussion" Repeat for *depression, irritability, social issues/isolation*. "Tell me about your child's ____ (anxiety/depression/etc.) before his/her concussion" (*prompt for whether this was an issue before the injury and, if so, to what degree*).
Key	• In thinking about your child's (*anxiety/depression/irritability/social issues*), what made those symptoms worse? • What seemed most helpful following your child's concussion? (*prompt for what helped at home and school, who were helpful people, and what specifically they did*). • *Encourage the participant to tell his or her story and to provide specific examples of how symptoms interfered with daily functioning and what was most helpful in improving symptoms.*
Conclusion	• In 2-3 minutes, briefly summarize the main points of the interview and ask if the summary is accurate. • When summary is completed, say, "Is there anything else you want to tell me about your child's concussion(s) that you think will help me better understand how to help other students?" • "Thank you for participating in this interview with me. I may be in touch at a later date to ensure that all the information recorded was an accurate representation of your experiences."